NEWBORN SCREENING NEWS

The California Newborn Screening Program **Summer 1996**

California's Newborn Screening Program

The California Department of Health Services has developed, with ongoing input from state and national experts, an efficient and effective newborn screening program. This mandated statewide screening program is centrally managed by the Genetic Disease Branch (GDB) of the California Department of Health Services. This article describes California's Newborn Screening (NBS) Program, and the roles and responsibilities of some of the key participants as defined by: the California Health and Safety Code, NBS Program Regulations[1] and recommendations, and the recommendations from the American Academy of Pediatrics (AAP), Committee on Genetics[2]. The State is in the process of updating NBS Program Regulations to address early testing and changes in health care delivery that impact newborn screening. Included are interim guidelines related to early testing based in part on the document *Early Hospital Discharge: Impact on Newborn Screening, Statement of the Conference March 31 - April 1, 1995* approved by the Council of Regional Networks for Genetic Services in February, 1996. We urge pediatric care providers, health officers, hospital administrators, medical directors, and nursing managers to share this article with their staff, particularly those who are in some way involved in the screening process.

The NBS Program currently screens for phenylketonuria (PKU), galactosemia, primary congenital hypothyroidism, and sickle cell disease and other hemoglobinopathies. Detection in the neonatal period permits early treatment with special diets for the metabolic disorders of PKU and galactosemia, and with thyroid hormone for primary congenital hypothyroidism. These measures prevent the development of mental retardation and other disabling conditions. Detection of sickle cell disease in newborns makes possible early entry into comprehensive care, which includes the initiation of penicillin prophylaxis and parent education, factors which have been shown to reduce mortality and morbidity.

Informing Parents of the Test

State Regulations require that prenatal care providers give pregnant women informational material about the California NBS Program. The program pamphlet, *Important Information for Parents About the Newborn Screening Test (IIP)*, describes screening and the diseases for which it tests. Because some women do not receive prenatal care, the IIP pamphlet is also distributed to women upon admission to a health care facility for labor and delivery. It is made available at no cost to all health professionals who serve maternity patients, to hospitals that provide maternity and/or newborn care, to local public health departments, and county birth registrars.

When to Collect Specimens

The timing of specimen collection is one of the key factors in the assurance of test validity and reliability. Because of the initial instability of a neonate's metabolic system, screening results of a specimen collected very early may not be reflective of an infant's true status.

Hospital practices of collecting NBS specimens at a routine time of the day or upon admission to the NICU can result in earlier than necessary testing. To safeguard against inappro-

*Analysis of California's newborn screening results (using its current testing methodology) demonstrates that collecting specimens from newborns who are at least **12 hours old** will detect almost all cases, while yielding an acceptable rate of false positives.*

1. California Code of Regulations, Title 17, Subchapter 9 Heritable Diseases, Sections 6500-6508.
2. *Pediatrics* 89(2), February 1992

priate early testing is imperative that providers/perinatal facilities adhere to the following NBS Program Regulations related to the timing of specimen collection.

- **All infants born in a licensed perinatal health facility must have a NBS specimen collected as close to discharge as is practical with the following exceptions.**

- **Infants remaining in the hospital for more than five days must have the NBS specimen collected on the sixth day of age.** If a newborn is transferred to another licensed health facility on or before the sixth day of age, it is the receiving hospital's responsibility to collect the NBS specimen. The screening of a critically ill infant may be postponed until the newborn's life threatening condition has stabilized.

- **Infants who are transfused with red blood cells (RBC), must have a specimen collected prior to the transfusion.** [Transfusions with plasma, platelets, or albumin will not affect the screening.] In post RBC transfusion specimens, the donor's hemoglobin type can mask the newborn's. The donor blood can also supply the enzyme that the galactosemia screening measures, so that the specimen collected from a transfused newborn with low enzyme levels could appear normal. Futhermore, the signs and symptoms of galactosemia may be masked in the newborn who is receiving only a non-milk based (lactose free) formula, e.g., soy, Nutramigen®.

When Newborn Screening Regulations were written, newborns' (and their mothers') hospital length-of-stay was at least 48 hours, and the mandate to test " ... as close to discharge as is practical" seemed to assure that specimen collection would occur at an appropriate time. However, the ever-growing practice of early hospital discharge (as early as eight hours after birth) has led to a significant increase in the percentage of babies tested before 12 hours of age. The AAP and ACOG statements on early discharge do not support discharge before 12 hours for healthy full term newborns. We agree that few newborns should be discharged at this early age. To assure optimal screening results and therefore considerably reduce the chances of missing a case the NBS Program strongly recommends the following practices and procedures:

- NBS specimens should be collected from healthy full-term babies when they are **at least 12 hours of age.** The potential for a missed case is increased if a specimen is collected earlier than this, especially during the first six hours of life.

- For infants who are not transfused and are in the hospital for less than six days of age, the NBS specimen should be collected **no earlier than two hours prior to discharge.**

For infants requiring transfusions:

- If the newborn is **less than 12 hours of age when the pre-transfusion specimen is collected,** even if the original test screen is negative, **a second specimen is to be collected** no sooner than 24 hours post-transfusion and no later than the sixth day of age. The pre-transfusion specimen provides valid results for galactosemia and hemoglobin, the second specimen yields valid PKU and hypothyroid results.

- If an adequate specimen was not obtained prior to transfusion, one should be collected sometime between 24 hours post-transfusion and the sixth day of life. In addition, the baby should be retested **three months** after the last transfusion in order to **determine the hemoglobin type**.

- Infants who have received intrauterine transfusions should have an initial screening and also be retested for hemoglobin type three months after the last transfusion.

The timing of specimen collection should never be determined by staff convenience. Collecting NBS specimens at a routine time of day or upon admission to the NICU, regardless of the infant's age or the probability of an immediate transfusion, is not sound medical practice and is not in compliance with the State Regulations. Any hospital that deviates from the State Regulations exposes itself to liability in the event of a missed case. In 1995, the Department of Health Services received a report of the first missed case of PKU in California since the expanded program began in 1980. The NBS specimen was collected at two hours of age upon admission to an NICU. The results were negative, well within the normal range. The baby had an extended stay and was never transfused. Therefore, there was no justification for testing the baby at such an early age. According to State Regulations, this baby should have been tested at six days of age.

Hospital well-baby nursery and NICU protocols must, at a minimum, reflect current NBS Program Regulations. It is strongly recommended that they also reflect the guidelines outlined in this newsletter. For assistance in developing or modifying procedures to meet State Regulations and recommendations, contact the Newborn Screening Follow-up Coordinator in your area.

Very early testing has resulted in a large increase in the number of false positives and, more importantly, at least one known missed case.

At this time, the decision to retest a newborn due to early specimen collection, except in the case of early testing due to a transfusion, is left to the newborn's physician. As a matter of policy, the State does not include coverage of a second test on the basis of age at time of collection. Test results mailed to physicians indicate the age of the newborn at the time the specimen was collected and the quantitative PKU test result. The newborn's physician is responsible for complete evaluation of NBS results and for any individual follow-up deemed necessary. If you are concerned with a newborn's negative phenylalanine level because of age at the time of specimen collection, do not use the Newborn Screening Program to repeat the phenylalanine test. Your local NBS Follow-up Coordinator, a registered nurse (listed at the bottom of every NBS result) can be of assistance in locating a laboratory that can run a phenylalanine test.

Completing Demographic Information on NBS Specimen Collection Form (NBS-I)

Accuracy and completeness of **all** the information provided about the newborn (on the demographic form attached to the filter paper) is very important for several reasons:

- The date and time of birth, birthweight, date and time of specimen collection, information on transfusion status, and race are all critical for evaluating the newborn screening results.
- NBS results are sent to the physician of record as listed on the demographic form. Incorrect or incomplete physician information delays or prevents receipt of the mailer, thereby potentially delaying timely follow-up.
- Should follow-up be needed on a newborn who has already been discharged, the newborn's complete address is necessary for locating the infant.

When a second specimen is collected because of a transfusion prior to 12 hours of age, it is critical that both previous "**transfusion**" and "**other repeat**" boxes are checked. It is also important to write the date and time of the transfusion.

Ensuring Testing of All Infants

The NBS Program has several mechanisms in place to ensure testing of all babies born in California. State NBS Regulations specify reporting requirements for both licensed perinatal health facilities and county registrars to ensure testing. All newborns must be tested; **the only legal ground for refusal** is a conflict with religious beliefs. The following procedures and forms are utilized to ensure testing.

Perinatal facilities must review each newborn's medical record within 14 days from the date of discharge to determine that the NBS results are filed in it, or that a parent's or legal guardian's signed refusal is present.

Perinatal facilities must review each newborn's medical record within 14 days from the date of discharge to determine that the NBS results are filed in it, or that a parent's or legal guardian's signed refusal is present. If it has been determined that a newborn was not tested, the facility must notify the infant's physician and the NBS Program. If a specimen was collected (as indicated by the presence of the goldenrod copy of the specimen collection form) but there is no NBS Results Mailer in the chart, the facility must complete a Missing Result Form (see below) and submit it to the State within five days.

Newborn Screening Missing Result Form (NBS-MR):

Used by perinatal licensed health facilities when an NBS specimen was collected but no results have been received.

Hospital Report of Newborn Screening Specimen Not Obtained (NBS-NO):

Used by perinatal licensed health facilities to report infants discharged without an NBS test, including those transferred to another hospital before a specimen is collected.

County birth registrars are required to notify persons registering the birth of a baby born outside of licensed perinatal health facilities of newborn screening. The registrars are also required to notify the NBS Program of these births via the NBS-OH form.

Notification of Registration of Birth Which Occurred Outside of a Licensed Health Facility (NBS-OH):

Used by county birth registrars to report babies born outside of a licensed health facility.

Important Information for Parents About the Newborn Screening Test (IIP) :

Birth registrars are required to give this pamphlet to the person registering the birth of a baby born outside of a licensed health facility and not admitted to a hospital within 30 days of the birth.

It is essential that the NBS-NO and NBS-OH forms be mailed promptly to the State NBS Program. The state follows-up on each of these forms to make sure the baby has been tested. Unless there is a record of parent refusal on file, the State refers all untested babies under one year of age to the Newborn Screening Follow-up Coordinators for assistance in obtaining the test. If you delayed in sending us the forms, we are delayed in getting the babies tested, which in turn could delay treatment if a baby has one of the disorders of which newborn screening tests.

Initial Laboratory Data Entry and Testing

California has been divided into six geographic areas, each with a private laboratory that performs from 60,000 to 114,000 NBS tests annually. Kaiser-North and Kaiser-South screen their members' newborns. Together, these eight newborn screening laboratories operate under a State contract. The laboratories use State-owned equipment, and the reagents used are either provided by or approved by the State. The laboratories follow the test protocols developed by the State Genetic Disease Laboratory. The demographic data and test results are entered by the laboratories on terminals linked to the GDB central computer in Berkeley. The quality of analysis and accuracy of reporting are monitored by State staff on a daily basis. Other monitoring procedures include proficiency testing and laboratory site visits.

Results Reporting

A report of each baby's initial test results (Newborn Screening Results Mailer) is mailed to the hospital that drew the specimen and to the newborn's physician of record noted on the demographic sheet of the screening form. This NBS Report Mailer should be in both the hospital chart and the pediatric care provider's office chart.

As in all screening programs, most of the tests are negative. If the initial screening test is presumptive positive, or if the sample is not adequate for testing, the mailer provides information on follow-up procedures. If a baby has been transfused, or if there is an unusual hemoglobin pattern, the mailer may also recommend independent follow-up outside of the NBS Program.

Pediatric care providers should review the result mailers of **all** children under one year of age. The physician providing well-child care will not automatically receive the NBS result mailer unless (s)he is the pediatric provider noted on the specimen collection form. A copy of the NBS Results Mailer can be obtained by contacting the State Department of Health Services, Genetic Disease Branch office or your Area Genetic Center, Newborn Screening Follow-up Coordinator.

Follow-up of Presumptive Positive Results from Initial Screening

The newborn and prenatal screening (NAPS) laboratories immediately report all initial presumptive positive test results by telephone to the assigned NBS Follow-up Coordinator. These state-funded coordinators are located at the fourteen Area Genetic Centers (AGC) throughout the state. Their offices are linked by computer to the central office of the Newborn Screening Program in Berkeley. The coordinator from the AGC telephones the newborn's physician noted on the NBS collection form to provide information about the test and the necessary follow-up procedures.

The primary care physician is responsible for notifying the family about the test results and for obtaining a recall specimen. The physician may request assistance from the NBS Follow-up Coordinator in this matter. Parents are also notified of the initial positive test result by letter from the Coordinator. Enclosed with the letter is a pamphlet that explains the meaning of an initial positive screening result and the need for recall testing.

A copy of the letter and the pamphlet are also sent to the newborn's physician. The Coordinator tracks all presumptive positive cases to ensure that appropriate follow-up occurs.

When a physician is not available, or fails to obtain a recall specimen, the Coordinator contacts the family directly to help make the necessary follow-up arrangements. The Coordinators can locate most families; however, assistance is occasionally requested of the local health department in the follow-up of an infant. Locating and informing parents may be an urgent matter since the risk of irreversible damage to affected infants is significant. All local health officers are responsible for making every effort to obtain Newborn Screening Specimens when requested by GDB or an AGC. Public health nurses may be called on to assist with obtaining initial specimens for out-of-hospital births and for repeat testing for inadequate and presumptive positive results [CCR 17, Section 6507.1 (b)].

Recall/Confirmatory Testing

If a test is presumptive positive, a second blood sample (called a "recall specimen") is collected. The recall blood samples for phenylketonuria are sent to the State Genetic Disease Laboratory (GDL) for testing. Samples for hypothyroidism are sent to GDL and/or a private laboratory. Recall specimens for galactosemia are sent to the State-approved galactosemia confirmatory laboratory, while those for sickle cell disease and related hemoglobinopathies are sent to the State-approved hemoglobin confirmatory laboratory. Confirmatory testing is a critical step in the screening process. There are several variables that can cause a false positive initial screening results for PKU, galactosemia, and/or hypothyroidism. The percent of false positive test results for PKU and congenital primary hypothyroidism are much higher in specimens collected before 24 hours of age than those collected later. This is due to natural biological variation, temporary surges in hormones, and delayed functioning of enzymes in the first 24 hours. Other factors that increase the false positive rate include: prematurity/low birth weight, hyperalimentation, mother's medications during pregnancy, and exposure of the specimen to heat. California's screening methodology for sickle cell disease is highly accurate, resulting in virtually no false positives; however, confirmatory testing is still necessary to determine the type of sickle cell disease. In addition, confirmatory testing for significant non-sickling hemoglobin patterns is necessary to rule out Beta thalassemia and other hemoglobinopathies.

Follow-up of Confirmed Positive Screening Results

The NBS Follow-up Coordinator notifies the newborn's physician of the recall test results. For confirmed positive results, the Coordinator will provide information on the confirmatory test and explain the recommended follow-up. Medical consultants are available at each AGC to provide additional information and consultation when necessary. Because primary care providers are often unfamiliar with these rare disorders, Coordinators can also assist the provider in referring a family to a California Children's Services (CCS) approved Metabolic, Endocrine or Sickle Cell Disease Center for specialized diagnosis and treatment.

Parents play an active role in close monitoring of these conditions and in treatment regimens consisting of special diets and/or daily medication. For children with sickle cell disease, it is critical that parents be skilled in identifying early warning signs of health problems that require prompt medical attention. Educational materials developed by the Program and distributed through health care providers provide practical information and support to parents. Upon request to the NBS Program, educational materials are available at no cost to health care providers, hospitals, clinics and local health departments.

Funding of the Program

State legislation provides a funding mechanism for this program. Hospitals or other facilities providing maternity care purchase newborn screening specimen collection forms at the rate of $1 per form. They are currently charged $41 by the State for each test panel completed by the screening laboratory. This fee covers all services, including recall testing and follow-up, if necessary. Facilities may charge patients, or their insurance companies no more than $42 for these tests; they may also charge up to a maximum of $6 for collection and handling of the specimen. Families of infants that require a second blood specimen collection because the initial specimen was inadequate may not be charged for the second collection. However, when a second blood specimen is

required due to a pre-transfusion specimen being collected prior to 12 hours of age, the hospital will be charged the full rate for the second specimen. The hospital can then in turn pass the cost on to the patient or their insurance company. Each month the number of tests collected at the facility is totaled and invoiced by the State. The money collected is deposited into the Genetic Disease Testing Fund which pays for all program costs.

Benefits of the Program

The program has been in operation since October 30, 1980. Approximately 99 percent of the babies born in California are tested. As of June 30, 1995 the program has screened 7,443,147 births and has detected 2,271 cases of primary congenital hypothyroidism, 287 cases of PKU, and 92 cases of galactosemia. The Genetic Disease Branch began screening for sickle cell disease on February 27, 1990. Clinically significant diseases detected by the program include **sickle cell disease**, (sickle cell anemia, sickle hemoglobin C, sickle hemoglobin D, sickle hemoglobin E, and sickle Beta thalassemia) **Beta thalassemia major**, and **hemoglobin E/Beta thalassemia**. This screening process was incorporated into the existing NBS Program, with testing performed using the same filter paper collection form which is used for the other three disorders. Presumptive positives cases are referred to existing CCS Approved Sickle Cell Disease Centers. Through June 30, 1995, the Program screened 3,015,720 infants for hemoglobin disorders, and 808 cases of sickle cell disease and other hemoglobinopathies were detected.

Disorders Detected by the Newborn Screening Program

Disorder	FY94-95	1980-1995*	Birth Prevalence Rate
PKU			
Classical	15	287	1:25,934
Variants	23	258	1:28,849
Primary Congenital Hypothyroidism	187	2,271	1: 3,277
Galactosemia	5	92	1:80,904
Sickle Cell Disease	120	689**	1: 4,508
Other clinically significant hemoglobinopathies ***	15	119	1:26,925

* October 30, 1980 - June 30, 1995
** Since February 27, 1990
*** Excludes homozygous EE

The test for sickle cell disease also detects some hemoglobin traits. Over 8,000 newborn carriers have been identified, most of whom have sickle cell trait. Although most hemoglobin traits are associated with few or no medical problems, the State offers carrier testing. The value of carrier detection is the opportunity to educate families, to test family members, and to provide genetic counseling to families at risk for a clinically significant hemoglobinopathy in future pregnancies. All physicians of infants with hemoglobin traits (FAS, FAC, and FAD) are notified by mail of the test results, as are the infants' mothers. In addition, because of the severity and high frequency of sickle cell disease, the Newborn Screening Program funds, via contracts, three regional Sickle Cell Counseling Centers (SCCCs). The SCCCs provide free voluntary counseling and testing for families of infants identified as carriers of hemoglobin S (sickle cell) trait, hemoglobin D trait or hemoglobin C trait. These services are available at the SCCCs and their many satellite sites.

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Limitations of the Newborn Screening Program

The California NBS Program provides exceptionally rapid turnaround time of screening results. This is critical to an infant's outcome, since many studies have proven the benefits of early diagnosis and treatment. Overall, the California Program has done quite well in identifying infants with PKU, galactosemia, primary congenital hypothyroidism and sickle cell disease. However, newborn screening programs are, by nature, imperfect. In setting cutoffs, a balance must be struck between time, money, anxiety caused by false positives, and an acceptable number of missed cases. Biological variability and/or human error can result in missed cases. Transfusions can lead to false negative screening results. Errors can occur at the specimen collection site, when the specimens are in transit, at the laboratory, in computer processing of results and/or in the reporting process. The California Program has numerous educational and monitoring mechanisms in place to prevent and investi-

gate any possible problems. However, it is still critical for health care providers to remain watchful for any sign or symptoms of these disorders in their patients. The possibility of a disorder should not be ruled out solely on the basis of the newborn screening test result. **A newborn screening result should not be considered diagnostic, and cannot replace the individualized evaluation and diagnosis of an infant by a well-trained, knowledgeable, health care provider**.

Reporting Requirements

To help evaluate the completeness and effectiveness of the program in detecting disorders, it is important for health care providers to report to the Newborn Screening Program any diagnosed case that was not detected by screening. California Code of Regulations, Title 17 requires that all physicians making a diagnosis of a preventable heritable disorder for which testing is required report such diagnosis to the Department of Health Services.

For more information about the California Newborn Screening Program or for consultation regarding a baby's test result, contact the Newborn Screening Follow-up Coordinator within your region.

Questions and Answers

◆ *How long will it take to receive a results mailer for my patient once the newborn screening specimen is collected?*

After being collected, the specimen takes about one to five days to get to the regional laboratory. Within one to two days of laboratory testing, all inadequate and presumptive positive initial test results are called out to physicians; however, the written report takes longer. The test results are transmitted via computer from the regional laboratory to Berkeley. It takes three days for testing by the regional laboratory and quality control review by the State laboratory. Once reviewed, the results mailer is sent from Berkeley to the hospital and the physician of record. On average you should allow 10 to 14 days from the time the specimen is collected until the physician of record and the hospital receive the Newborn Screening Results Mailer. Please keep in mind that local mail delivery service may affect the time it takes to receive the results from the NBS Program.

NBS Program Regulations require that hospitals check their records for newborn screening results 14 days after the baby's discharge and to notify the NBS Program of any missing results.

◆ *How does the NBS Program define six days of age or sixth day of life?*

Six days of age as defined by NBS Program means from the time a baby begins the sixth twenty-four-hour period until it is ended, i.e., 120 -144 hours.

◆ *I have sent the NBS Program an address correction several times and my patients' NBS results are still being sent to my old address?*

The NBS Program keeps a database with physicians' names and addresses used for mailing correspondence such as this newsletter and for redirecting any NBS results that are undeliverable and returned by the post office. If your NBS results are being sent to the wrong address, please contact the nursery of the hospital that is listing the wrong address on the NBS specimen collection forms and advise them of your address change. Frequently there are some old standing orders that need correcting.

◆ *How long after a protein feed must we wait before collecting the NBS specimen so that the PKU screen is valid?*

A protein feed is not necessary before collecting the NBS specimen. A newborn has been receiving phenylalanine in utero. California's laboratory testing methodology is a very sensitive quantitative one that does not require a further protein challenge. Therefore, follow the guidelines as outlined in this newsletter for collecting specimens after 12 hours of age.

◆ *I noticed the NBS specimen collection form has a box for CORD BLOOD, does this mean that we can use cord blood rather than stick the newborns?*

NO! You should only submit cord blood to the NBS Program if a newborn has been transfused prior to the heelstick NBS collection. If you still have available a nonhemolyzed cord blood specimen that is also free of clots, you can spot it on the filter paper, identify the specimen as cord blood and report the specimen collection date and time to be the same as the birth date and time. The combination of a cord blood specimen (valid for the galactosemia and hemoglobin screens) and the 24-hour post transfusion specimen (valid for the PKU

and hypothyroidism screens) will allow you to obtain a complete screen for a transfused newborn.

Important Phone Numbers

NBS Results Mailers: (510) 540-2611

NBS Forms: (510) 540-3302

NBS - I (Specimen Collection Form)
NBS - NO (Report of Specimen Not Obtained)
NBS - OH (Report of Out of Hospital Birth)
NBS - MR (Missing Results Form)

NBS Accounting: (510) 540-3038

NBS Educational Materials: (510) 540-3295
including the pamphlet *Important Information for Parents*, (the purple one).

GeneHELP Resource Center

The GeneHELP Resource Center has over 550 titles of materials on a number of genetic diseases, hemoglobinopathies, birth defects, as well as newborn screening and prenatal diagnosis issues. GeneHELP searches for and reviews new genetic health education materials on an ongoing basis. With many types of formats ranging from pamphlets, brochures and curricula to videotapes and slides, there is one to suit your patient population. Health care providers can request a variety of services including computer printouts of reviewed materials, consultation in selecting/developing materials, sample copies of certain educational materials, and computer searches for information on materials. Please call (510) 540-2534 for more information on what new materials are available.

Newborn Screening Coordinators at Area Genetic Centers (AGCs)

UC San Francisco	(415) 476-5048
UC Davis	(916) 754-5400
Children's Hospital, Oakland	(510) 428-3127
Stanford University	(415) 723-7987
Fresno Valley Children's Hospital	(209) 225-8738
Loma Linda University	(909) 824-4191
UC Los Angeles	(310) 825-9719
Children's Hospital, Los Angeles	(213) 669-2226
LAC/USC	(213) 226-3816
Harbor/UCLA Medical Center	(310) 222-3751
UC Irvine Medical Center	(714) 456-6878
San Diego-Imperial Counties Developmental Services	(619) 576-2975
Kaiser Permanente, Northern Calif.	(510) 596-6192
Kaiser Permanente, Southern Calif.	(818) 564-3326

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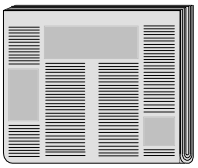

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Readers are encouraged to submit comments, questions or ideas for future articles.